

#### Terms of Reference: Report writer consultant

#### GUIDE Asthma - A patient-friendly report (deadline for applications: November 21st 2022)

EFA is a vibrant alliance of 45 European allergy, asthma and chronic obstructive pulmonary (COPD) patient associations from 26 countries and works for equal access to good quality care, safe, healthy environment and patient participation.

In 2022, EFA plans to assess the Global Initiative for Asthma (GINA) <u>patient guide</u> and start developing a patient-friendly report based on the GINA annual report, which currently only addresses medical audiences. EFA will seek to work closely with GINA and the European asthma patient community to achieve this awareness raising and patient empowering project. The end result will be a tool that offers patients and carers accurate and scientific information to keep them up-to-date about treatment plans and options. It will also serve as a tool for healthcare professionals to support their asthma patients and provide them with guidance.

EFA is looking for an external consultant to help conducting a desk review on the existing asthma patient education material and drafting the report.

## Background and Project Description

Given the chronicity of asthma, patients and carers are faced with different moments and needs to treat their disease over time. Many patients are avid to find scientific and accurate information about prevention, disease progression and treatment options, to support the exchanges they have with healthcare professionals and the system in general. However, according to EFA ACCESS survey, only one in three asthma patients in Europe does not feel involved in decision-making processes about their therapy and they often feel they are not presented with personalised tools to be able to self-manage their disease<sup>1</sup>. Moreover, 20% of asthma patients in the survey stated that they have "never heard about" written self-management plans.

Asthma guides are tools designed to help patients prevent worsening and better manage their disease. They are often produced by scientific or research bodies, and sometimes by patient organisations. However, there are concerns within patient communities around their efficacy and availability, due to existing gaps in knowledge and awareness of the asthma patient experience, what patients regarding self-management and disease progression, and what it takes to access tailored healthcare to address their needs.

To empower asthma patients in handling their treatment, GINA developed evidence-based strategy documents to guide patients on asthma management. GINA is a global organisation launched in 1993 in collaboration with the World Health Organization. It works with healthcare professionals and public

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health officials around the world to produce resources and intitiatives to reduce asthma prevalence, morbidity, and mortality.

The '<u>GINA patient guide: you can control your asthma</u>' is a patient-friendly guide for asthma management with a lot of potential to grow as a reference resource for patientes worldwide.

The objective of the project is to review the current information, and to expand it to be more useful for asthma patients and healthcare professionals, in close collaboration with GINA and the European asthma patient community. The result will be an updated GINA annual report (designed for healthcare professionals) targeting patients, build on the input of asthma patients, so that asthma patients can be better supported across their care.

# Scope of work

The consultant will implement **a desk research** to explore the existing educational material for asthma patients across Europe, considering also the results of an internal survey conducted by EFA workshop organised by EFA for its members and the global asthma community, with the aim to discuss and collect best practices at national level.

The consultant will then **draft the patient-friendly report** based on <u>GINA annual report</u> and taking into consideration the gaps identified with the desk research. It will need to address different audiences such as children and teenager patients, adult patients, and carers.

The report will have a digital, interactive format, and shall be written in a patient-friendly manner and contain accurate scientific information that will help asthma patients. It will contain an evidence-based asthma management strategy for the use of patients.

The work will be developped under the management of EFA and in collaboration with GINA and other medical associations.

## **Expected Outputs**

The work will result into the development of a patient-friendly report on asthma management that will be widely disseminated by the asthma patient community and presented to the medical respiratory community worldwide.

## Deliverables and Timeline

The consultant will be responsible for the delivery and quality of the final product. All deliverables shall be submitted to EFA in accordance with the following timeline:

Task/Output	Target due date
Desk Review	13/01
Report first draft	13/02
Report second draft	06/03

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Report third draft	27/03
Final Report	07/04

# Qualifications of the Consultant

Professional Experience	Proven experience in the life sciences sectors
	Track record in drafting and editing materials targeting lay audiences,
	especially on disease management
	Proven past experience in medical desk research and analysis (desired)
	Experience working with patients' groups and medical societies
	(desired)
Language requirement	Native level English

## **Proposal Submission**

Interested applicants should submit a detailed offer, including CV, examples of work and short motivation, to valeria.ramiconi@efanet.org by 21<sup>st</sup> of November 2022. Short-listed candidates will be invited to a meeting in the week of 28<sup>th</sup> of November 2022, in person or virtual, to present their offer and address questions.

EFA ACTIVE ASTHMA AND COPD PATIENTS ACCESS CARE REPORT<sup>i</sup> https://www.efanet.org/images/ShowLeadership/Report-Showleadership\_FINAL.pdf